

Why Patient-Centered Research Practices Are Worth It

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Learning Objectives

- Recognize common practices in the clinical research setting that are not patient-centered.
- What do patient-centered practices look and feel like? What are the benefits? (To the patient, to you, to your organization, to your study sponsors)
- How can you lead by example when you are in a work environment that is not patient-centered or does not prioritize the patient's experience?



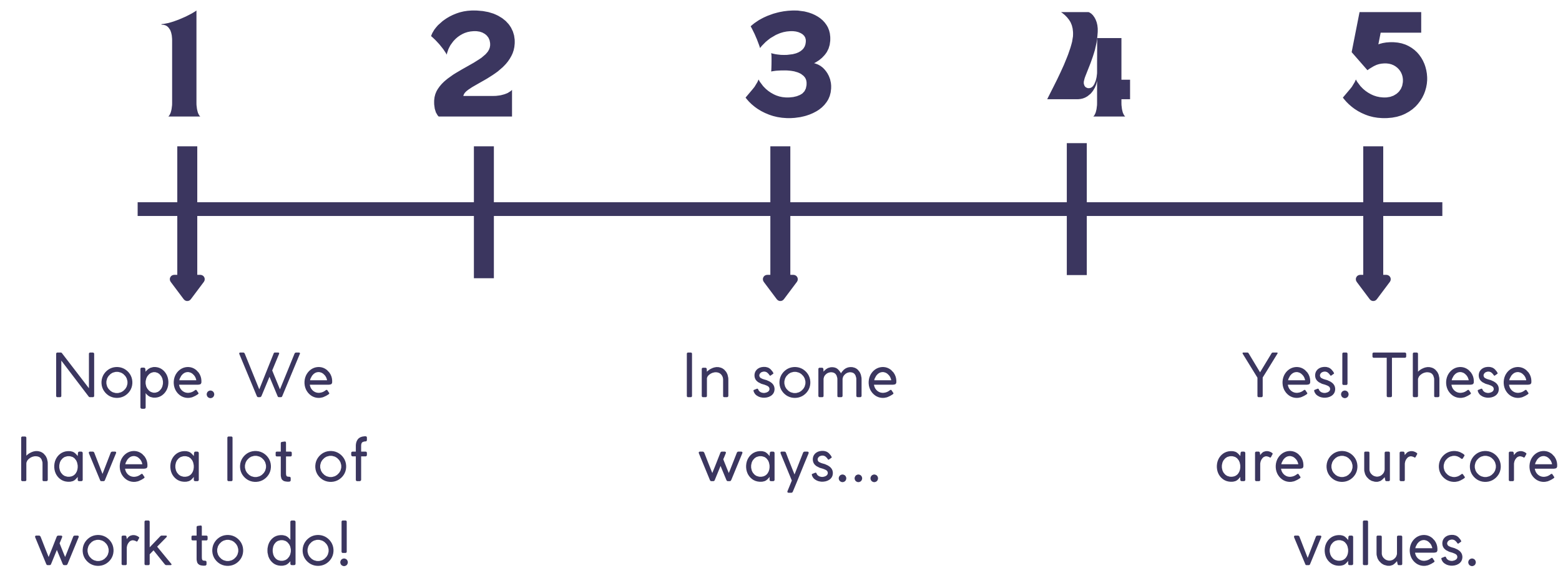
Credit: Dmytro Zinkevych



Credit: Dario Valenzuela

Poll #1

Think about the values and practices at your current or most recent work environment. Are patients respected, valued, and given ownership over their experience as a research participant?



My interactions with patients are typically...

Fast
paced

Fun

Joyous

Insightful

Quick

Talkative
or chatty

Heart
warming

Virtual

In-
person

Sad

Sweet

Stressful

Lengthy

Meaningful

Easy
going

Energizing

Exhausting

Serious

Agenda

- Brief history on patient interaction practices
- Definition of Patient-Centered Research
- Accessibility – Integral to Patient-Centered Research
- Transforming common practices into Patient-Centered Practices (team work!)
- Benefits to our work

A Brief History on Patient Interaction in the U.S

1900s - 1950s

Paternalistic model.

Physician knows best.

Patient simply listens and follows orders.

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1950s/60s

Patient centered
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1950s/60s

Patient centered
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2000s

Patient centered research
begins to be seen as a core
value of research.

A Brief History on Patient Interaction in the U.S

2010s

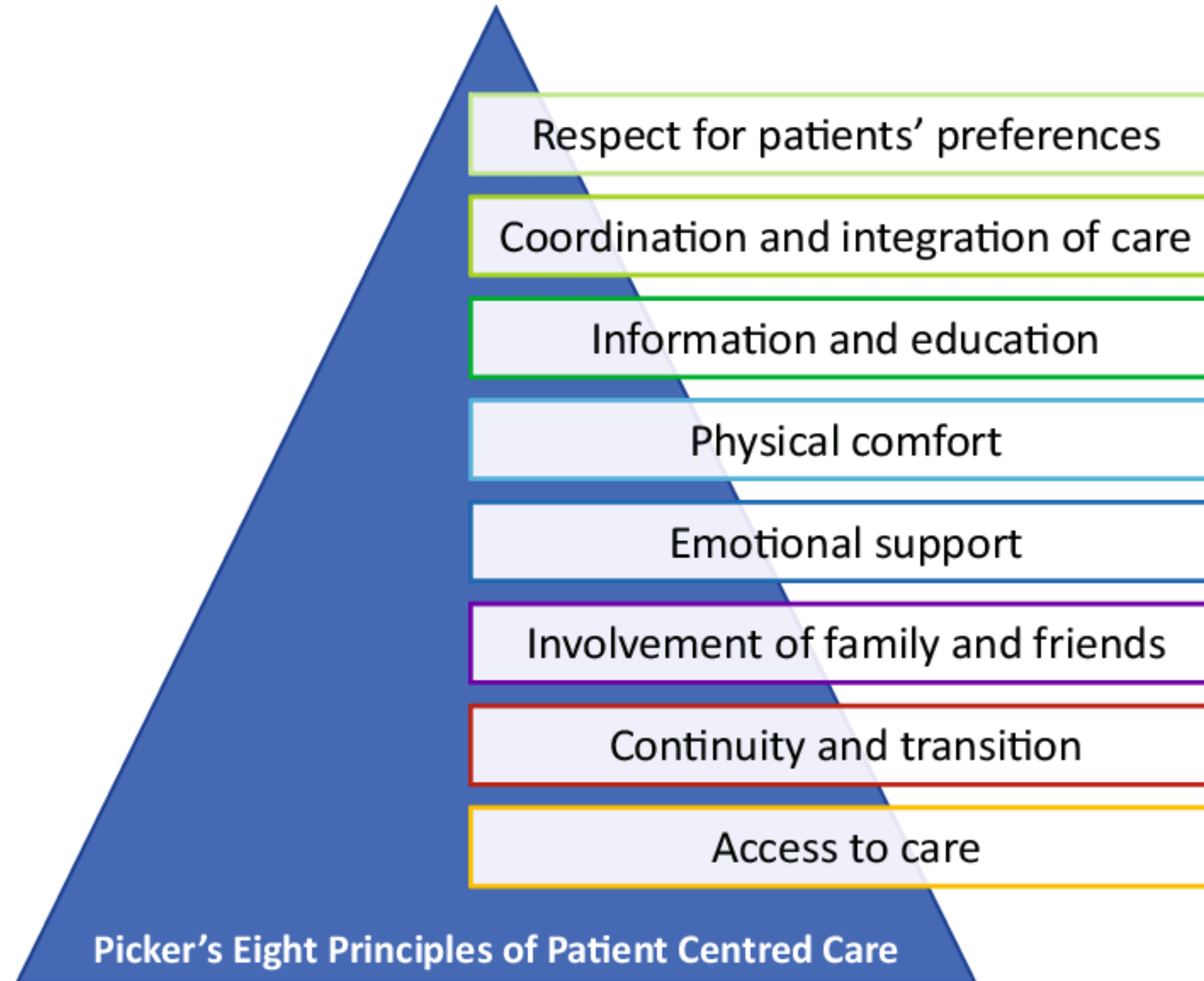
- Wide range of knowledge on illnesses via the internet.
- Patients can learn about clinical trials going on worldwide
- Patients can connect over their lived experiences with other patients via social media, support groups, forums, etc.

A Brief History on Patient Interaction in the U.S

2020s – Present

- Pharmaceutical companies make it a point to invest in patient centered research and projects
- Recognition of how our personal identities influence our ability to ask for and receive the care that we need (race, gender, income, language, immigration status)

What is patient-centered care?



What is patient-centered research?

The core belief, as the foundation of all of your research activities, that “patients are unique living beings,” always and at all times deserving of respect, and that you have an obligation to “care for them on their terms.”

(Epstein, Street, 2011)

Patient-Centered Research is incomplete without Accessibility

for the Patient, their Family, and their Caregivers



Poll #2

What languages do your
patients and their families
speak?

Poll #3

What is the literacy level of your patient population and their caregivers?

Accessibility

The one CRC that speaks Spanish



Accessibility

1. Language and Literacy

- Patients need (and deserve) to be understood in the language that they speak
- Literacy can impact a patient's interest and comfort with participating in research
- Visually Impaired Patients
 - “Speak Aloud” in Microsoft Word misinterprets things occasionally

Accessibility

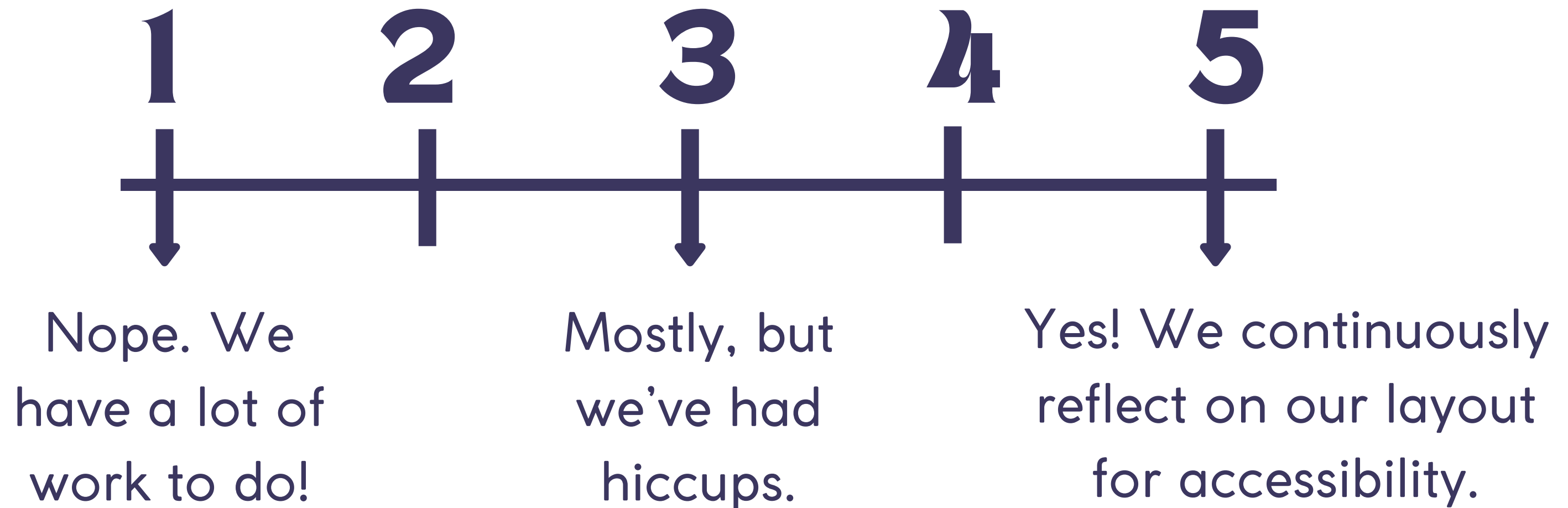
2. Building and Room Access

- Easy access in and out of the hospital, rooms, and bathrooms for all patients.
- Consider height of seating, size of seating in waiting room
- Can the patient access the bathroom, sit comfortably, and have privacy?

Accessibility

Poll #4

Consider the room/floor/area where you primarily recruit patients.
Does this area seem accessible for all of the patient's needs?



Accessibility

3. Values, Culture, and Religion

- How can we adapt our research practices to best fit the values and identities of each unique patient?
- Consider Muslim patients participating in fasting during Ramadan.

Accessibility

THE FINAL SPRING 2025 GAIT SESSION HAS A NEW DATE: SUNDAY, APRIL 27.

In Person: Honoring Faith While Providing Care: Person-Centered Approaches for Older Adult Muslims in Health Care



Date: Sunday, April 27, 9 a.m. - 5 p.m.

Location: American Muslim Senior Society, 1319 Apple Avenue, Silver Spring, MD 20910

Participants in this GAIT project will explore the principles of person-centered, culturally competent healthcare with a focus on mental health. Gain an understanding of how traditions, language, cultural values, and religious beliefs shape health practices and influence delivery of care within the older adult Muslim community. Through presentations and interactive discussions, attendees will have the opportunity to apply inclusive approaches to build trust, improve communication, and enhance health outcomes.

Transforming common practices into Patient-Centered Practices

Let's learn from each other's experiences!

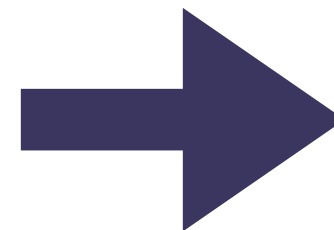
Transforming common practices into patient-centered practices

Common practice:

Clinical research coordinator
completes survey about sensitive
health topics with patient in the
waiting room

Reasoning:

Convenience, limited number of
examination rooms, speediness



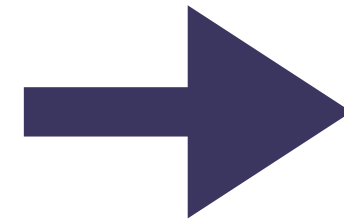
Patient-Centered Adaptions

**Team, any
suggestions?**

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Patient-Centered Adaptions

- Try to get a private room
- Be transparent with the patient and ask them what they prefer.
- White noise machine
- If allowed, wear regular clothing or your scrubs in order to not draw attention to you and the patient
- If you can't take an exam room, you might go into a room that isn't used as often (like a conference room).

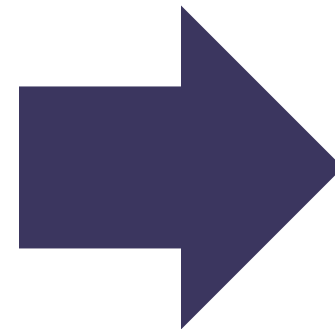
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Patient-Centered Adaptions

1. Give the patient the opportunity to share their preference by stating: "In this survey, I'm going to ask you personal questions about your physical and mental health. We have a couple of options, let me know which one you prefer. You could complete the survey on your own or we could complete the survey together. I would read the questions out loud to you and you can share your answer with me to write down. We could complete the survey after your appointment in the waiting room or if you prefer privacy we could complete it over the phone at a time that works best for you."

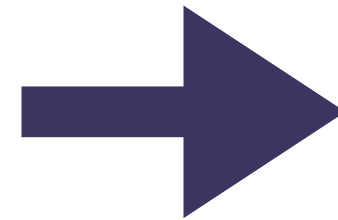
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Common practice:

PI's getting very focused on enrollment numbers (rather than patients being the right fit for the study)

Reasoning:

Pressure from study sponsor, deadlines, funding, passion project.



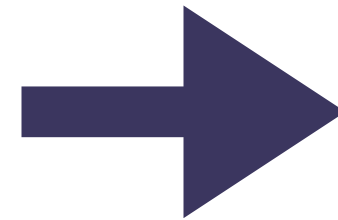
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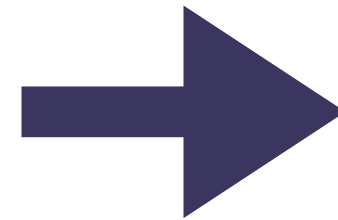
Patient-Centered Adaptions

- Recognize your own emotions. Do you feel pressured to encourage patients to enroll that don't appear interested?
- Release that weight from your shoulders. Consider that each patient does deserve to at least hear about the study and the decision to enroll is theirs, not the PI's or yours.

Transforming common practices into patient-centered practices

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Patient-Centered Adaptions

Tip from a former CRC:

- Keep a tracker on Excel that captures each eligible patient that came into the clinic that day, shows that you approached them, and their response (enrolled/declined). Include a column for the patient's reason for declining (if given).

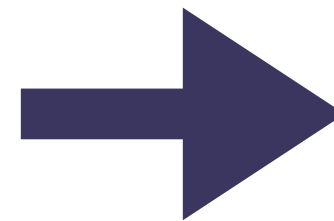
Transforming common practices into patient-centered practices

Common practice:

A study/survey about one topic taking the opportunity to ask many more (less related) questions, resulting in a very long survey.

Reasoning:

To get as much info as they can (to have enough variables to find significance for publishing)



Patient-Centered Adaptions

Team, any suggestions?

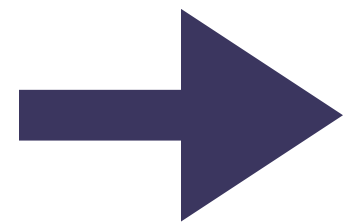
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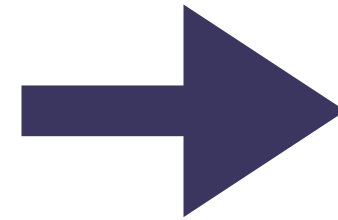
Patient-Centered Adaptions

- Recognize what you can and can't control.
- As the CRC or recruiter for the study, be honest with the patient about the time commitment but also the benefits (helping advance research and improve services for future patients).
- If patients in the study have complaints about it, consider if there is a way to relay that information to the PI (mention to PI that patients feel its too long, too repetitive, etc.)
- PI may have the ability to make a protocol amendment, but accept that they might not.

Transforming common practices into patient-centered practices

Common practice:

A colleague wants to vent
about a patient that is
annoying them



Reasoning:

Overworked or exhausted,
seeking comfort/help

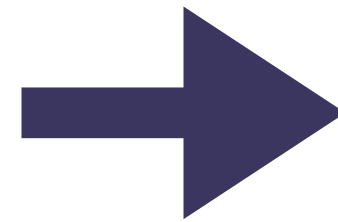
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Patient-Centered Adaptions

- Consider asking the colleague to speak in a private area that is not accessible to patients, such as your office.
- You can hold space for what your colleague is feeling while also maintaining respect towards the patient and what they may be experiencing.
- Consider another colleague/CRC interacting with the patient instead.

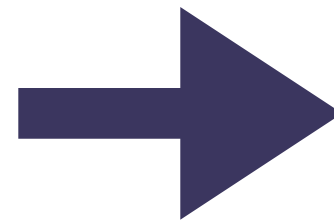
Transforming common practices into patient-centered practices

Common practice:

Making comments outside of the patient's medical care (their clothing style, the way they speak, where they're from, political affiliation) and treating patients differently because of how they present.

Reasoning:

Judgement, bias, venting,
discomfort



Patient-Centered Adaptions

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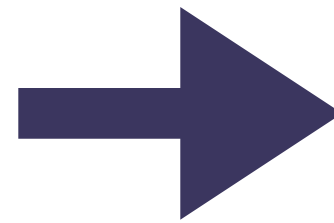
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Patient-Centered Adaptions

- Model appropriate behavior at all times, even if your supervisors or colleagues with seniority are making those comments.
- Remain calm and redirect (if needed) to the patient's medical care. Don't engage in that sort of conversation.
- When writing notes, keep it specific to their medical care/needs.

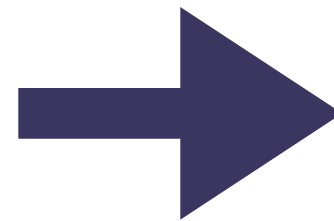
Transforming common practices into patient-centered practices

Common practice:

Let's think of one!

Reasoning:

**Patient-Centered
Adaptions**



These ideas are great and all but...

**everyone is too busy
to listen to me**

**how can I get my
colleagues to do this
too?**

The attitude is go go go!

**I just have to
get it done!**

**I'll be labeled as
difficult if I speak up**

**The Pls don't care
what the patients
think**

I'm soo tired

What do we bring to the office/hospital on any given day?

Patient

Stuck in traffic

Had to take time off work

Scared of the unknown

Excited to help advance research

Will my wheelchair fit through the
bathroom door?

I get to see my favorite nurse today!

Am I doing enough?

Research/Medical Staff

Devoted to healing

Juggling deadlines

Gotta grab dry ice!

Do I have time for lunch today?

I get to see my favorite patient today!

I wish I could speak Spanish...

Benefits of Patient-Centered Research

1. Patients feel valued, they feel appreciated for providing help to solve a problem or develop new techniques/treatments.
 2. Study Adherence
 3. Retention
 4. Alignment with our mission to support patient's healing.
 5. Funding shortages will require creative adaptations.
- Empowering patient's voices will make it easier to provide solutions that meet their needs.

**Without the patients, we have no
research.**



References

1. Epstein, R. M., & Street, R. L. (2011). The values and value of patient-centered care. *The Annals of Family Medicine*, 9(2), 100–103. <https://doi.org/10.1370/afm.1239>
2. ISPOR–The Professional Society for Health Economics and Outcomes Research. (n.d.). Patient-centered research. ISPOR.org. <https://www.ispor.org/education-training/learning-lab/patient-centered-research>
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